REPORT TO THE TWENTY-THIRD LEGISLATURE STATE OF HAWAII 2005

PURSUANT TO HOUSE CONCURRENT RESOLUTION NO. 141, REQUESTING THE DEPARTMENT OF HEALTH TO ESTABLISH A COORDINATED STATEWIDE EFFORT TO ADDRESS FETAL ALCOHOL SPECTRUM DISORDER

PREPARED BY:
STATE OF HAWAII
DEPARTMENT OF HEALTH
HEALTH RESOURCES ADMINISTRATION
FAMILY HEALTH SERVICES DIVISION
MATERNAL AND CHILD HEALTH BRANCH
OCTOBER 2004

Report on House Concurrent Resolution No. 141

Requesting the Department of Health to Establish a Coordinated Statewide Effort
To Address Fetal Alcohol Spectrum Disorder

October 12, 2004

I. <u>Introduction and Background</u>

The 2004 Hawaii State Legislature passed House Concurrent Resolution 141 (HCR 141) recognizing the need to understand the nature of the problem of Fetal Alcohol Spectrum Disorder (FASD) in Hawaii, as well as to address the lack of FASD-specific resources. The resolution directs the Department of Health (DOH) to spearhead efforts to coordinate a better understanding of the issues surrounding FASD prevention and intervention. This report summarizes the DOH approach and response to the resolution, provides a brief description and analysis of the problem of FASD, and gives some background on recent organizing activities.

Fetal alcohol spectrum disorder (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy and refers to conditions such as fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). FASD is a leading cause of mental retardation and neurologic deficit in the United States and its manifestations may range from severe to mild. Prenatal alcohol exposure resulting in birth defects and damage to the central nervous system is a cause of serious disability, handicap, and impairment. The neuropsychiatric complications from prenatal alcohol exposure result in cognitive impairment, impaired

attention, impaired socialization skills, poor decision-making and gross structural brain malformations. These factors predispose to social difficulties, involvement in the criminal justice system, increased use of alcohol and other drugs, and thus provide a high potential for generational transfer of impairment (May & Gossage, 2000).

DOH first began to formally organize around the issue of FASD in 2003, when an MCHB representative attended the first "Building FASD State Systems" meeting in Florida sponsored by the FASD Center for Excellence. The training focused on helping states identify organizing tasks to develop a statewide system of infrastructure building and public awareness of the disease spectrum. As part of the organizing effort to educate providers, MCHB and Healthy Mothers Healthy Babies (HMHB) sponsored Mr. Dan Dubovsky, an expert FASD trainer and facilitator, to present a series of lectures and presentations around the State in the fall of 2003. The next organized event in Hawaii, coordinated by DOH (Family Health Services Division (FHSD)-MCHB and the Alcohol and Drug Abuse Division [ADAD]), was the two-day Intervention Touchpoints Conference and Town Hall meeting in March, 2004. MCHB began collecting names of individuals interested in working together on a statewide task force. Because of MCHB's involvement in this issue the Branch is currently serving as the lead for the task force. To date a small group of core individuals has met to plan the initial internal efforts. Currently, a meeting of DOH Division and Branch Chiefs is scheduled for October 19, 2003 to discuss the coordination and intersection of this issue within the Department.

Ms. Ginny Wright, community organizer, educator, and Mom of an adopted child with FAS and Dr. Cynthia Goto, FHSD Medical Director, attended the May, 2004 Center on Excellence conference as Hawaii's State Team.

II. Description of the Problem

Data for Hawaii, as for the U.S. as a whole, is insufficient at best. However, MCHB is collecting more definitive information through the Perinatal Risk Assessment Monitoring Survey, or PRAMS system.

Hawaii has had no recent active case ascertainment studies conducted examining FASD specifically. However, a recent active case ascertainment study looking at crystal methamphetamine provides valuable information with respect to FASD. A 2003 study examining crystal methamphetamine use during pregnancy tested the meconium of 436 newborn infants in Hawaii. Surprisingly, researchers found an unexpectedly low number (0.7%) of specimens positive for crystal methamphetamine while 5.3% of these mothers reported alcohol use during pregnancy of which 0.9% reported drinking during the third trimester. However, when meconium was tested for the fatty acid ethyl ester (FAEE) metabolite which is indicative of alcohol use, an alarming 17.1% of the mothers tested positive for the alcohol metabolite. These findings prompted the researchers to state, "Concern over illicit substance use should not preempt continued and increased emphasis on identification and prevention of prenatal exposure to alcohol" (Derauf, et al, 2003).

Epidemiological studies of FASD as well as studies of alcohol abusing and

dependent women, consistently indicate that maternal health variables are among the most common and consistent risk factors for FASD. Many studies have identified health-related risk factors such as co-use of tobacco and other drugs (NIAAA 2000) as well as social variables, most significant being low SES, as having been found to be associated with FASD births (Abel 1998).

A steady rise in prevalence and consequence indicators related to substance abuse, child welfare services intervention, poor mental health, and criminal behavior have created public concern in Hawaii. Providing prevention and intervention services for children and adults affected by or at risk for FASD is extraordinarily challenging since service needs cut across multiple delivery systems that typically have had difficulty coordinating efforts. Additionally, lack of a focused definition of the problem and need across sectors and lack of identified resources to pursue additional system development, have prevented cohesive statewide planning or organizing efforts to directly address this issue.

There is also the issue of ethnic disparities related to FASD which must be examined. Native Hawaiians and Part Hawaiians typically suffer the highest disparities related to morbidity and mortality in a host of conditions, to include heavy drinking and poor pregnancy outcomes. In general it has been found that Native Hawaiians use more alcohol than the other ethnic groups in Hawaii (Hishinuma, 2000), and have higher rates of problem drinking which include both acute (binge) and chronic drinking (Office of Hawaiian Affairs, 2002).

These figures are particularly alarming considering that an increasing body of data suggests that some minority groups suffer more adverse effects from alcohol

consumption, abuse, and alcoholism than do other populations. This issue is so significant that in 2001 the National Institute on Alcohol Abuse and Alcoholism (NIAAA) developed a Strategic Plan to Address Health Disparities as part of a major effort within the National Institutes of Health to reduce differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States.

What this indicates is that any FASD initiative must be sensitive and cognizant to issues of language, acculturation, and cultural norms.

III. <u>Implementation</u>

The issues related to FASD touch a number of Divisions within the DOH. As FHSD-MCHB has participated as one half of the State lead through attendance at two FASD Center for Excellence system-building conferences, MCHB did meet in June, 2003 to plan how to proceed with the task force. The MCHB staff felt that the effort would be best served if a DOH internal agency meeting could be held to discuss how the work involved in statewide system building would proceed and be shared amongst all internal stakeholders.

Subsequent to the internal DOH leadership meeting, a gathering of interested community collaborators will be convened. Part of the complexity of the statewide system-building effort is that there are no resources assigned to the issue and the need for a comprehensive assessment will require resources. Given the distribution/assignment/allocation of current resources there is a paucity of effort.

In order to offset some of the costs involved in organizing the statewide effort, MCHB applied for a one-year planning subcontract with Northrop-Grumman IT, a subsidiary of the Substance Abuse and Mental Health Services Administration (SAMHSA). This award would allow for funding for the task force, development of a needs assessment and strategic plan for FASD in the State.

IV. Recommendations

MCHB would like to request that the resolution be extended for an additional year to facilitate the accomplishment of the tasks as outlined. More time is needed for the Department to organize the effort both internally and externally, so that the work of the task force can proceed in a comprehensive manner. A focused effort will result in a plan that will best address the needs of Hawaii's women, children and families.

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